

## THE INDEPENDENT LIVING AND DISABILITY RIGHTS MOVEMENT: BERKELEY, 1962-1979 A Documentation Project and Research Platform

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A new research platform on the independent living and disability rights movement will be available for use in late 1999 at The Bancroft Library at the University of California at Berkeley. The inauguration of the archive will mark the completion of Phase I of a documentation project funded through a Field-Initiated Research grant from the National Institute of Disability and Rehabilitation Research.

Phase I of the project, referred to as the Disabled Persons' Independence Movement (DPIM), began in 1996 to document the Berkeley portion of the movement from 1962 to 1979. The resulting 45 oral histories (from 2 to 25 hours in length, transcribed and bound) and 250 linear feet of catalogued materials from both interviewees and the major disability organizations in Berkeley are designed to aid scholars in study of the origins and development of the movement.

Funding permitting, Phase II will begin in 1999. In addition to further oral histories and collection of papers, Phase II will create a digital archive, accessible via the Internet, to include full-text oral histories, archival collection guides, and a large representative collection of manuscript and visual records. The fourth component of Phase II will offer technical assistance to other regions in the nation to facilitate preservation and access to manuscripts and the collection of oral histories.

### Genesis of the Project

The genesis of this project was two-fold. First, it became obvious over time that the explosion of ideas and organizations that had occurred in Berkeley in the 1970s had been somewhat phenomenal. Written accounts, however, were generally superficial, often embellished, even mythological. Nonetheless, Berkeley had become an important symbol. Books and articles, both national and international, unfailingly cited Berkeley as a pioneer.

But the full story had yet to be told. Lengthy and focused recorded interviews of leaders and key participants offered one solution and would provide primary source material for future researchers. Timing was urgent; several leaders had died by the mid-90s.

A second concern for future scholarship was the paper documentation of the movement. What existed in Berkeley was scattered and inaccessible in all senses of the word. Some organizations, in need of space and in short staff, ignored or were discarding their oldest records. Boxes of invaluable materials were stored in individuals' basements and attics, in critical need of preservation and permanent quarters.

In 1995 one particularly valuable set of "boxes" surfaced at the time of the death of Dr. Kirk McGugan who had been working on a dissertation on the history of the movement. Her mother entrusted McGugan's materials to Mary Lou Breslin who in turn sought advice from The Bancroft Library, one of the largest special collections in the nation.

Then Curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum, Director of the Regional Oral History Office (ROHO) at the Bancroft, in support of the idea of a disability collection. Baum, Hardwick and Ann Lage, Deputy Director of ROHO, worked with leaders of the local disability community to design a plan for a research platform of oral histories and collected materials based on the established procedures and experience of their respective units.

## Primary Source Material

The nature of this documentation project is to collect primary source material. The interviews and the collection of papers will yield detailed information on subjects of general interest: identity issues; development of the concept of independent living; race, class, and gender issues; development of community group identity; impact of technology; leadership, institution-building, sustaining of organizations; the range of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Although it is too soon to proffer definitive themes (before the project is completed), several lines of inquiry already suggest themselves: what drew people with disabilities to Berkeley; the importance of context once they arrived; the significant role of women, the predominance of wheelchair-users, the low numbers of people of color, and the role of nondisabled people in the early movement; the ways in which the community transcended volatility and contentiousness for purposes of broader policy; leadership characteristics; organization-building; development of mythology in a movement.

## Project Team

The procedures for developing the oral histories and for collecting materials are described at the end of this article.

Approximately fifteen people work part-time on this project. In addition to the above-mentioned administrators, there are seven interviewers, an archivist and assistants, transcribers, and office staff.

The interview team, in consultation with an advisory board of five faculty from three universities, set the boundaries and objectives of the project. They also developed the list of prospective narrators and of organizations likely to have important historical materials. The archivist independently works with the organizations, identifying, collecting, and processing papers, photographs, and other materials. She follows up each completed oral history with a request for personal papers from the narrator.

## Narrators

Narrators (interviewees) are selected for one of several reasons: the individual was part of an important group, was a founder or recognized leader, made a unique contribution, was a particularly keen observer and articulate reporter, was a sustainer of the movement or, in a few instances, was a significant leader outside of Berkeley.

Narrators for Phase I fell naturally into two categories: either they were involved in the Residence Program of Cowell Hospital on the Berkeley campus in the 1960s or they participated in the building of early organizations in the 1970s.

### Group One

A wing on the third floor of Cowell Hospital was the site of the first housing for students with severe disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students - mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp - spent several years in this benign, but nonetheless isolated hospital residence, in the middle of a campus exploding with free speech, civil rights, and antiwar activities. Six of these students discuss their lives and activities, collectively revealing the nature of this seminal period.

We interviewed Ed Roberts who narrated several hours of 1960s memories before he died, two presidents of the loosely formed political entity called the "Rolling Quads" initiated by the students at the hospital, the first female student, and the first African-American student. They all refer to

their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

In this first group, we also included certain early University and Rehabilitation officials who might be called traditional gatekeepers, but nonetheless allowed the unorthodox Residence Program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities.

### Group Two

The second group of narrators are primarily founders and leaders who participated in the more explosive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the University, followed by the founding of the Center for Independent Living (CIL) two years later. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause," seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. Programs that got their start at CIL and soon after became independent (Computer Technologies Program, Disability Rights Education and Defense Fund, Berkeley Outreach Recreation Program) are included, providing insight into the politics, leadership, and organization-building of both their own organization and CIL.

Many key narrators in this group are still in leadership positions and have had national and international impact on disability policy development.

We included people in this section who were not in the top ranks of leadership, but who were keen observers of the scene, could augment the basic history, and offer further points of view. Most were staff of the organizations; about half were people with disabilities. Group Two includes about thirty people.

### Groups Three and Four

Phase II will include two more categories of 50 to 60 narrators.

Group Three will include representatives of the hundreds of people with disabilities who were attracted to Berkeley during the seventies. Many were quickly snatched up by the local disability community to run a wide variety of projects or sustain organizations. Some initiated new organizations, some were political activists; others pursued the arts, occasionally achieving recognition in the national disability community. Others initiated work in the international arena.

This group as a whole was more diverse than the leadership in types of disability, gender, color, although probably still not typical of a random population. Frequently well-educated, they developed a strong sense of belonging to a newly significant community and ardently articulated the notions of independent living and disability rights. This group, demonstrating abundant possibilities, may be key to an explanation of why Berkeley came to be viewed as a symbol of the movement.

The final group of narrators will be individuals from outside of Berkeley, from California as well as seven other regions in the nation with early centers of movement activity. In addition to a national perspective on the origins of the movement, this group of interviewees will hopefully provide an overview of important issues, organizations, and local participants to facilitate future documentation by prospective regional historical projects.

## **The Process of Oral History**

Oral history as practiced by the Regional Oral History Office is conducted by trained oral history interviewers with subject-matter expertise in the issues to be documented. A preliminary outline is prepared before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. Systematic, in-depth interview sessions of 1-2 hours in length are tape recorded; interviewees in this project

required from 1 to 15 sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes are transcribed verbatim and lightly edited for accuracy of transcription and clarity. Interviewees are asked to give additional information when needed. The final edition adds subject headings, a table of contents, and an index.

The forty-five oral histories of Phase I (approximately 5000 pages of single-spaced transcriptions, representing 250 hours of tape-recorded interviews), bound with photographs, will be placed in the Bancroft Library and at the University of California at Los Angeles Library. If funding allows, the full-text transcripts as well as a large representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California. Permission of narrators is a prerequisite for Internet use.

Wherever possible, we record one videotaped interview session with participants to document visual elements of the interview and the setting in which the interviewee lives or works. Excerpts of these videos will be used online in the digital archive. Videos will also be available for patron viewing at The Bancroft Library.

It is the policy of the Regional Oral History Office to encourage research use of its oral histories. When the collection is available, researchers may apply to the director of The Bancroft Library for permission to publish substantial quotations from the interview transcripts. Unless the interviewee restricts access to publication of his/her interview in the legal agreement signed with the university, such requests are granted.

### **Collection of Institutional Records and Individual Papers**

The collection of personal papers of narrators and records of organizations are the responsibility of the archivist. For each organization included in the project, the archivist (a) conducts a records survey to determine the amount and kind of records generated by the organization, (b) identifies those materials of permanent historical value, (c) formulates a records management program to ensure the preservation of vital records and archival materials, and (d) works with the organization on the placement of its records at The Bancroft Library or other archives.

The collections of institutional records and individual papers are described to the file folder level in finding aids (the inventories, indexes, and descriptive summaries that describe in detail the context and content of archival collections of manuscripts, pictorial materials, and other collections of primary source materials).

The DPIM finding aids, created in electronic form if funding permits, will be available worldwide through the Internet, and will form the framework for the project's digital archive. It is hoped that, as archival repositories are developed by others nationwide, their finding aids will be incorporated in the DPIM Digital Archive, thus creating a "virtual archive" of national interest.